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ABSTRACT

This briefing paper provided background information and a preliminary report of the achievements and future needs of the Federal Part H Program of the Individuals with Disabilities Education Act (IDEA) and its services to infants and toddlers with disabilities and their families. This collaborative federal, state, and local partnership created a framework for the nationwide development and implementation of comprehensive service systems. The paper is organized around four questions: (1) What is early intervention and why is it important? (2) What is the Part H Program? (3) What have states achieved under the Part H Program? and (4) What are the future challenges for the Part H Program? Examples of family experiences with early intervention are given. References and contact information for members of the Ad Hoc Part H Work Group, the U.S. Department of Education, and state and jurisdictional Part H Program coordinators are included in the appendices. Appendix 4 lists the states/jurisdictions approved for full implementation of Part H of IDEA in 1993 and 1994. Appendix 5 lists Part H lead agencies by state. (SG)

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ED 452 673

Helping Our Nation's Infants and Toddlers with Disabilities and Their Families

A Briefing Paper on Part H of the Individuals with Disabilities Education Act (IDEA) 1986–1995

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A Preliminary Report Submitted to the Federal Interagency Coordinating Council
April 20–21, 1995

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A Briefing Paper on
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Disabilities Education Act (IDEA),
1986-1995

A Preliminary Report Submitted to the
Federal Interagency Coordinating Council
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Contents

Page

What Is the Purpose of This Briefing Paper? **1**

Why Is Early Intervention Important? **3**

What Is the Part H Program? **5**

What Have States Achieved Under the Part H Program? **11**

1. Early Intervention Policies, Programs, and Services Are More Beneficial for Children and Families 11
2. Early Intervention Services Are Proving to Have Cost Benefits 12
3. Services Are Improved and Streamlined by Interagency Coordination and Collaboration 12
4. State and Local Service System Development Is Enhanced 13
5. More Children Are Being Identified and Served Through Expanded Services 14
6. More Personnel Who Are Qualified to Work with Young Children With Disabilities Are Available to Provide Services 14
7. Legislation and Funding Are Supporting the Continuation of Early Intervention Services 15

What Are the Future Challenges for the Part H Program? **17**

Family Support Needs to Be Further Strengthened 17

Maintain the Quality of the Early Intervention System and Its Services 17

Assure That Personnel Are Fully Qualified 18

Assure Adequate Funding for the Early Intervention System and Its Services 18

Moving Part H Into the 21st Century **19**

References **20**

Appendices:

1. Members of Ad Hoc Part H Work Group 21
2. U.S. Department of Education Contacts 23
3. State/Jurisdictional Part H Coordinators and ICC Chairs 25
4. Status of States and Jurisdictions for Eighth and Seventh Years of Funding (FY 1994 and 1993) of Part H of IDEA 37
5. List of Part H Lead Agencies 39

Contents, *continued*

Tables:

1. Minimum Components of a Statewide, Comprehensive System of Early Intervention Services to Infants and Toddlers With Special Needs 7
2. Services That Can Be Provided Under Part H 8

Letters:

1. A West Virginia Family's Experience With Early Intervention 4
2. An Idaho Famliy's Experience With Early Intervention 15

What Is the Purpose of This Briefing Paper?

This briefing paper is intended to provide background information and a preliminary report of achievements and future needs for the Federal Part H Program of the Individuals with Disabilities Education Act (IDEA) and its services to infants and toddlers with disabilities and their families. This collaborative Federal, state, and local partnership has created a positive framework for the nationwide development and implementation of comprehensive service systems.

The paper is organized around four questions:

- Why is early intervention important?
- What is the Part H Program?
- What have states[1] achieved under the Part H Program?
- What are the future challenges for the Part H Program?

Information was gleaned from various sources to address these questions. This includes extant information from various documents such as Federal Part H Applications and information submitted voluntarily by 30 states in early 1995. This material was then summarized around common themes by an Ad Hoc Part H Work Group of volunteers. *(See Appendix 1 for their names and contact information.)* The National Early Childhood Technical Assistance System (NEC*TAS) facilitated the final compilation of this preliminary report.

We hope that this briefing paper will be informative to representatives of the Federal Interagency Coordinating Council (FICC) and other individuals interested in Federal, state, and community program development and services for young children and their families. If readers have any particular questions about the Part H program, please contact your state's Part H lead agency or ICC Chair, the Part H staff of the Early Childhood Branch of the Office of Special Education Programs (OSEP) in the U.S. Department of Education, staff at NEC*TAS, or individual members of the Ad Hoc Part H Work Group who guided the development of this briefing paper. *(Refer to Appendices 1, 2, and 3 for contact information.)*

[1] Throughout this paper, "states" is used generically to refer to all governmental jurisdictions, including the 50 states, the District of Columbia, and territories.

Why Is Early Intervention Important?

Research shows that growth and development are most rapid in the early years of life. Learning begins at birth and involves a constant interaction between the child and the environment. A child with a disability or a significant developmental delay may be more limited in his or her ability to interact with the environment than a typically developing child and may not acquire many basic skills. The earlier in a child's life that problems or potential risks are identified, the greater the chance of eliminating or minimizing existing problems or preventing future problems through early intervention.

Recent studies confirm the effectiveness of early intervention programs. The Infant Health and Development Program (Ramey et al., 1992), a national multi-site study, found that low-birthweight, premature infants who received comprehensive early intervention services scored significantly higher on tests of mental ability, and experienced lower mental disability rates compared to children who received only health services. The Early Intervention Collaborative Study (Shonkoff, Hauser-Cram, & Upshur, 1990) found developmental gains after one year of intervention in children with identified disabilities or who were at risk for developmental problems.

Many children are born every year who would benefit from early intervention services. Advances in medical technology during the last 30 years have increased the survival rates of infants born prematurely or with disabling conditions. Other children with no presenting birth problems may exhibit developmental delays during the early years or may become disabled through injury.

At the same time, our ability to provide the wide range of services needed by infants, toddlers, and young children with disabilities and their families has grown. More than ever, we are challenged to provide this wide range of services at the time when maximum benefit can be derived from them. All medical, health, education, and social service professionals working with these young children and their families have an important role in facilitating access to early intervention services.

Early intervention services are designed to help children with disabilities reach their maximum potential and become as independent and productive as possible by:

- promoting development and learning for children who receive the services;
- identifying and providing timely intervention and treatment for children with health and developmental problems or who are at risk of developing problems;
- decreasing the need for costly special programs later;
- providing support to parents at a critical time in their child's life and enhancing their capacity to meet their child's needs; and

- coordinating services within the community to improve access for families and assure the best use of available resources.

Early intervention services mean different things for different people and depend on the specific needs of the child and family. Federal legislation and related funding support the development of state and community service systems to meet the health, social, and developmental service needs of young children with disabilities and their families.

Letter No. 1
A West Virginia Family's Experience With Early Intervention
(A mother's letter to the West Virginia Part H Coordinator)

When my son was born in August 1993, he was diagnosed as having Down syndrome. I went through the normal grieving process that I refer to as the Shattered Dream Syndrome. Many thoughts raced through my head those first few days about my family's future. One of the thoughts was that having a child with special needs would require so much of my time and energy. Another thought that I had was that I would always have to care for my son.

We started a center-based early intervention program when Paul* was 2 weeks old. . . . My son receives physical therapy, occupational therapy, speech therapy, developmental services, and service coordination. During the first year, service coordination helped me obtain a medical card to ensure that Paul would receive medical services above and beyond that of what my insurance pays and what we can afford. Paul had chronic fluid in his ears the first year of his life that hampered his development. As soon as tubes were inserted, the early intervention staff and my family has seen tremendous progress in *all* areas of his development. The staff is able to really work with him and help him reach developmental milestones. Paul just started signing the word "eat," a milestone which parents of normally developing children may not be able to fully appreciate. . . .

The dream is no longer shattered. Early intervention is implemented in our home in such a natural way. Each sibling does their own thing with their baby brother. My older son roughhouses with the baby which contributes to his gross motor development. My daughters help feed him in a way that will help his oral motor development. Everyone in the family is signing basic signs. When I am shown a technique that will help Paul, I show the other kids who will assist with his needs. This sounds like work, but it really is nothing but fun. In my home I don't make a big fuss about early intervention services. I do make a fuss about quality family time and incorporate Paul's services into daily living routines.

It concerns me greatly that IDEA may be scrutinized in the near future. Early intervention services will ultimately save the taxpayers money in the future. My son, Paul, will not be as dependent on the system in the future, thanks to the services received through early intervention.

*The child's name has been changed to respect this family's privacy.

What Is the Part H Program?

Early intervention services are critical if we want to ensure that children with disabilities are able to reach first grade ready to learn. Such services may reduce the need for and cost of special education later for children who receive services early.

In 1986, the Congress passed landmark legislation, Public Law 99-457, which established a program for States to develop a comprehensive, coordinated, multidisciplinary system to provide infants and toddlers with disabilities and their families early intervention services. This approach was revolutionary in the delivery of human services because it made States coordinate and pool different funding sources in order to provide services to infants and toddlers with disabilities and their families.

Representative Bill Goodling (R., PA)
Congressional Record, September 11, 1991, p. H6405

With bipartisan support, the 99th Congress enacted and President Reagan signed into law on October 8, 1986, P.L. 99-457, the Amendments to the Education of the Handicapped Act (EHA).[2] This legislation is now known as the Individuals with Disabilities Education Act (IDEA). These Amendments reauthorized the EHA and included a rigorous national agenda to increase and improve services for young children with special needs, birth through 5 years of age, and their families. One major portion of IDEA invited states to expand and improve services to infants and toddlers with disabilities and their families: Part H, the Infants and Toddlers With Disabilities Program.

This national agenda was fueled by the needs of children and families and by the documented benefits of early intervention. A multiplicity of responsive, appropriate, inclusive, and high-quality services was proposed under Part H. Furthermore, the unique role of families in the development of their children was recognized, along with the importance of family participation throughout the policy development and service provision processes. Collaboration and coordination among existing Federal, state, and local agencies were considered to be critical to this process. The statutory language of Part H captures a vision of a comprehensive statewide early intervention system that includes all these critical features and more.

Through annual grants beginning in 1987, Part H has provided states with financial support to first develop and establish, and later maintain, a statewide system that offers early intervention services to all eligible children. Although

[2] This legislation was subsequently updated through amendments P.L. 101-476, the Individuals with Disabilities Education Act (IDEA), in October 1990; P.L. 102-119 and P.L. 102-421, amendments to IDEA, in October 1991 and 1992, respectively; and P.L. 103-382, amendments to IDEA in the Improving America's Schools Act of 1994.

participation in Part H has always been voluntary, every state has chosen to develop a statewide system and, as of October 1, 1994, has committed to seeing that services are available to every eligible child and his and her family within its borders.

Part H created a formula grant program to assist states in planning, developing, and implementing a statewide system of comprehensive, coordinated, multidisciplinary, interagency programs for all eligible young children with disabilities, birth to 3 years of age. Its preamble, as updated in 1991, included these findings and policy goals:

> (a) Findings
>
> (1) to enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay;
>
> (2) to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age;
>
> (3) to minimize the likelihood of institutionalization of individuals with disabilities and maximize the potential for their independent living in society;
>
> (4) to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and
>
> (5) to enhance the capacity of State and local agencies and service providers to identify, evaluate, and meet the needs of historically underrepresented populations, particularly minority, low-income, inner-city, and rural populations. (See 20 U.S.C. §1471(a))
>
> (b) Policy
>
> It is therefore the policy of the United States to provide financial assistance to States —
>
> (1) to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for infants and toddlers with disabilities and their families;
>
> (2) to facilitate the coordination of payment for early intervention services from Federal, State, local, and private sources (including public and private insurance coverage); and
>
> (3) to enhance their capacity to provide quality early intervention services and expand and improve existing early intervention services being provided to infants and toddlers with disabilities and their families. (See 20 U.S.C. §1471(b))

The goal of Congress, advocates, parents, service providers, the Executive Branch, and state administrators and legislators has been to create equal access to an intervention and prevention system for all of America's eligible children and families. Policy makers have sought to build upon existing systems, where appropriate, and to make public and private services available to families to the extent possible under Federal or state law.

Under Part H, each state and jurisdiction, in concert with its local communities, has been challenged to design a family-centered, responsive, collaborative, culturally sensitive, and high-quality service system with an emphasis on the provision of services in natural settings. Each system must include, at minimum, 14 specific components *(see Table 1)*. State and jurisdictional service systems are still at a relatively early stage of full implementation. Appendix 4 presents a short history of when participating states have assured that appropriate early intervention services are available to all eligible infants and toddlers and their families. The majority of states have been in the full implementation phase since September 1993.

The governor of each state or jurisdiction is charged to appoint a lead agency within state government to plan and oversee the operation of the comprehensive

Table 1

Minimum Components of a Statewide, Comprehensive System of Early Intervention Services to Infants and Toddlers With Special Needs

1. Definition of developmental delay
2. Timetable for ensuring appropriate services to all in need
3. Timely and comprehensive multidisciplinary evaluation of needs of children and families
4. Individualized family service plan and service coordination (case management) services
5. Comprehensive child find and referral system
6. Public awareness program
7. Central directory of services, resources, and research and demonstration projects
8. Comprehensive system of personnel development
9. Single line of authority in a lead agency designated or established by the Governor for carrying out:
   a. general administration and supervision
   b. identification and coordination of all available resources
   c. assignment of financial responsibility to the appropriate agencies
   d. development of procedures to ensure services are provided pending resolution of any disputes
   e. entry into formal interagency agreements
   f. resolution of intra- and interagency agreements
10. Policy pertaining to contracting or making arrangements with local service providers
11. Procedure for securing timely reimbursement of funds
12. Procedural safeguards
13. Policies and procedures for personnel standards
14. System for compiling data on the early intervention programs

Note. Adapted from 34 CFR §§303.161 through 303.176. See also 20 U.S.C. §1476(b).

Table 2
Services That Can Be Provided Under Part H
Services include but are not limited to:

- Assistive Technology Devices and Services
- Audiology
- Family Training, Counseling, and Home Visits
- Health Services
- Medical Services for Diagnosis or Evaluation
- Nursing Services
- Nutrition Services
- Occupational Therapy
- Physical Therapy
- Psychological Services
- Service Coordination Services
- Social Work Services
- Special Instruction
- Speech-Language Pathology
- Transportation and Related Costs
- Vision Services

Note: From 34 Code of Federal Register (CFR) §303.12(d).

early intervention system. A variety of agencies have been appointed to play this important role. *(See Appendix 5 for a list of Part H lead agencies.)* Additionally, an Interagency Coordinating Council (ICC) is appointed by each governor to advise and assist the lead agency. Each ICC has an appointed chairperson and is composed of various parent, agency, service provider, university, legislative, and insurance representatives.

The U.S. Department of Education, through its Office of Special Education Program (OSEP), distributes funds under Part H to the states to help them carry out collaborative systems planning, policy development, and implementation of needed services for infants and toddlers who have disabilities.[3] These funds also may be used to pay for the provision of direct services to children which are not otherwise provided for by public or private sources. *(See Table 2 for a list of these services.)* Monies also can be used to expand and improve services that already are available. Congress appropriated $50 million for the first year of this multi-year initiative (1987); $67 million for the second year; approximately $69 million for year 3; $79 million for year 4; $117 million for year 5; $175 million for year 6; $213 million for year 7; $253 million for year 8; and $316 million for year 9 which are available as of July 1, 1995. State appropriations are based upon a census formula. According to OSEP (NEC*TAS & OSEP, 1994), during fiscal year 1993 states reported using an average of 14% of their Federal Part H funds for administrative purposes, ranging from 0 to 36%. States reported that an average of 64% of their Federal Part H funds are used for direct services to children and families, ranging from 0 to 99%. As of December 1,1993,

[3] Under Part H, disability means a substantial delay in the child's development or an established condition which will cause a substantial delay in development. Each state must set its own criteria for what constitutes a substantial delay. At a state's discretion, eligible infants and toddlers may include those who are at risk of developing substantial developmental delays.

approximately 150,000 infants and toddlers were being served nationwide through state Part H programs.

The 1991 Amendments to IDEA established a Federal Interagency Coordinating Council (FICC). This Council is charged to ensure coordination and cooperation of the Federal early intervention and preschool special education programs and policies across Federal agencies. The FICC is composed of representatives from Federal agencies which sponsor programs and/or initiatives for this population, families, ICC chairs, State agencies, and others. The Council meets in Washington, D.C., on a quarterly basis.

On-going assistance is available to state Part H programs from OSEP staff and its sponsored National Early Childhood Technical Assistance System (NEC*TAS). NEC*TAS, a consortium project based at the University of North Carolina at Chapel Hill, provides continuous consultation, support assistance, and inservice education to help state program leaders, service providers, and parents plan and accomplish their early intervention system goals. NEC*TAS also supports the work of the FICC and collaborates with other national TA and resource initiatives. Also supporting the implementation of state early intervention service systems are numerous demonstration, data, and outreach projects funded by OSEP. Several OSEP-funded research institutes also have provided information and insights on service utilization, personnel preparation, transition, and state policies.

What Have States Achieved Under the Part H Program?

Part H . . . did far more than set out requirements and expectations...It explicitly stated and promoted a new value system. It challenged us to develop a system that would support and meet the needs of families, all families, regardless of their situation, culture or family structure. It asked States to develop interagency connections and to work collaboratively with other agencies serving families. It asked us to develop holistic systems eliminating the fracturing of services that previously existed. It did all this while giving States the freedom to develop systems that would meet our own unique needs and situations.

Part H Coordinator from Wisconsin

After 8 years of Federal support states in partnership with communities have achieved much of what was intended under Part H and more. Based upon information gathered to date from the states that submitted documents to the Ad Hoc Part H Work Group and from a review of other extant sources, seven areas of achievement are highlighted below.

1. Early Intervention Policies, Programs, and Services Are More Beneficial for Children and Families.

Before we can talk family values, we must value the family enough to say: "We will support you when you are most vulnerable. We will help you when you need it the most. We will offer you some supports and services that will give you a sense of stability and direction. We will offer you some hope."

Director, Developmental Disabilities Planning Council, Denver, Colorado

Part H challenges states and service providers to meet the developmental needs of the child through family-centered services which involve families as full partners with professionals. Many states are finding that family-centered service delivery is being adopted as best practice for all services for children. Family-centered services address family as well as child needs. Many states have established statewide family support networks to provide family-to-family support, pertinent information and resources to assist families of children with disabilities. Family-centered values and principles have been incorporated in states' planning and implementation of their early intervention systems. States report that the family-centered services to the child and family result in:

- improving child developmental and social adjustment outcomes;
- decreasing parental stress as a result of support and assistance in accessing needed services
- recognizing the family's role as decision maker and partner in the early intervention process on behalf of their children and themselves;
- helping families to make the best choices for their children by providing comprehensive information about the full range of formal and natural resources in their communities;
- accommodating individual child, family, and community differences through creative, flexible and collaborative approaches to services;

- valuing children and families for their unique capacities, experiences, and potential;
- seeking meaningful and active family involvement in the planning and implementation of family-centered and community-based services; and
- obtaining potential health care savings due to ongoing monitoring of health status and referral for primary health care and nutritional services.

2. Early Intervention Services Are Proving to Have Cost Benefits.

A number of states have undertaken general and targeted evaluation studies on the benefits of early intervention including cost benefits and savings. The states are finding evidence to support the cost benefits of early intervention services. The states describe the following benefits:

It has been our experience that a multidisciplinary team approach to providing care to children and their families improves the overall quality of life for the patients and their families. It is my personal belief that this also reduces institutionalzation and, therefore, the overall cost to the community and society.

Physician from Alaska

- positive benefit-cost ratios and future savings for every dollar spent in early intervention — e.g., Massachusetts reported a single year's savings of $2,705 per child after deducting the cost of early intervention services, Montana reports saving $2 for every $1 spent on early intervention by the time the child is age 7 and projects $4 saved for every $1 spent by age 18, and Florida projects a 20 year cost savings of $20,887 per child;
- need for fewer future services such as special education — e.g., Texas reports 20% of children receiving early intervention services need not be referred for special education, Montana reports 36 out every 100 children need no further special education through at least second grade and another 33 children need only limited services; and
- reduced need for more costly institutional or group home services — e.g., North Carolina reported a ten year study of 1,000 children showed that children receiving early intervention services were only half as likely to be referred for institutional or group home services as they grew older.

3. Services Are Improved and Streamlined by Interagency Coordination and Collaboration.

States have streamlined and/or developed organizational structures that have created collaborative coordination mechanisms that facilitate planning and decision making at the state, regional, and local levels, and empower families as collaborators. For example, 41 states include local interagency coordinating councils (LICCs) in their Part H system. In addition, states have or are developing coordination plans and interagency agreements with other initiatives that are also concerned with young children such as Head Start, developmental disabilities, GOALS 2000, maternal and child health, child care and development, mental health, Healthy People 2000, Title I and Even Start, and Medicaid. State achievements include:

- coordination of available Federal, state and private funds to support services to young children and their families;
- reduction of fragmentation and duplication of services and more effective use of existing resources;
- interagency sharing of responsibility for the planning and implementation of Part H;
- coordination with other Federal initiatives, such as health and Child Care and Development Block Grant, and with state child initiatives, such as prenatal care, child care, job training, child welfare, and adult literacy programs; and
- establishment of an Interagency Coordinating Council at the state level and local interagency councils to plan and support the implementation of coordinated services through interagency agreements between and among state agencies and their local affiliates.

We received support to cope with the unending challenges. Some of that support was through a responsive and seasoned professional and some was through the introduction to other parents who were experiencing some of the same issues.

Parent from Massachusetts

4. State and Local Service System Development Is Enhanced.

States have developed policies and resource materials to assure statewide implementation of an early intervention service system including such areas as: eligibility, individualized family service plans, service coordination, transition, natural environments, procedural safeguards, outreach and child identification, health care, and diversity. A wide range of community agencies have worked to build local service systems based on these policies through collaborative activities and the ongoing planning of local interagency councils. These agencies include social services and local public health agencies, private early intervention providers, public schools, local hospitals and clinics, child care providers, and community programs for families. Achievements through collaboration include:

- development of services which are easily accessible and widely dispersed throughout the community, and are culturally sensitive and tailored to individual family priorities;
- expansion of outreach and child identification through collaborative community screening and referral;
- development of options for home-based and community-based service delivery models in community settings in which children without disabilities participate;
- maximization of community resources by building on existing resources and integrating Part H requirements in existing practices;
- diversification and coordination of the service provider base with participation of a broad array of participants; and
- increased public awareness and support for early intervention issues.

5. More Children Are Being Identified and Served Through Expanded Services.

This month our son started kindergarten. He's already one of the most popular boys in school, is learning to share, and is learning to do much more than we had dared hope. We have the [early intervention program] to thank for much of his success.

Parent from Virginia

The number of children identified and receiving services has increased significantly through expanded outreach efforts and referral sources. According to the U.S. Department of Education, more than 150,000 children are reported to be receiving early intervention as of December 1, 1993. Before Part H, many areas of the country had very few services and resources available for infants and toddlers with disabilities and their families. Where services did exist, they were frequently fragmented and poorly coordinated. Since the passage of Part H, there has been a dramatic increase and expansion in a continuum of appropriate and coordinated services in the states. Achievements in expanding services include:

- since September 30,1994, all states are providing early intervention services for eligible children and families;
- eleven states have formally incorporated in their eligibility definitions at-risk populations to be served by the Part H program, and several other states are including children with combinations of risk factors in their definition of developmental delay; and
- states have implemented public awareness programs featuring child identification activities through media campaigns — e.g., Sooner Start (Oklahoma), Early On (Michigan) and BabyNet (South Carolina).

6. More Personnel Who Are Qualified to Work With Young Children With Disabilities Are Available to Provide Services.

I say provide the support and activity as early as possible, find staff that have the faith, and you will find that more and more children with challenges will discover that their challenges can be mastered to some degree, if not overcome. I have seen this with my own son.

Parent from Florida

States have increased the number of competent, qualified early intervention professionals and paraprofessionals through a variety of activities and strategies including:

- development of a comprehensive system of personnel development (CSPD);
- pre-service training experiences and recruitment incentives in collaboration with institutions of higher education;
- establishment of a competency-based system for credentialing and certification to ensure that the highest personnel standards are met;
- provision of creative, collaborative training and technical assistance and inservice training opportunities for early intervention practitioners and parents; and
- involvement of parents in the development and implementation of personnel training.

7. Legislation and Funding Are Supporting the Continuation of Early Intervention Services.

Children with special needs are born every day and they will become adults with special needs. Early intervention services help parents prepare these children to become adults that will not hinder, but contribute to society. Clearly it is so very critical that our grandchild and so many other children with special needs have services as early as possible.

Grandparent from Utah

Through the development of supporting legislation and administrative rules each state has improved accessibility to services, increased statewide supports for the program, and coordinated services with other community agencies and resources. States are funding their systems of early intervention services through multiple sources including: the annual Federal Part H grant, state appropriations, Medicaid, use of third-party insurance, private funding sources and, in some states, sliding fees. Achievements to date include:

- all states have developed either state legislation, executive orders, lead agency policies, and/or interagency agreements that authorize the operation of a comprehensive early intervention system;
- based upon an informal NEC*TAS analysis of state costs for early intervention, Federal Part H monies support 16% of the total costs of early intervention services; and
- all states are designing and undertaking to coordinate the use of multiple funding streams to enable their systems to operate more effectively and efficiently. For example, 47 states report using Medicaid to fund portions of their Part H program.

Letter No. 2
An Idaho Family's Experience With Early Intervention
(A mother's letter to the Idaho Part H Program)

On August 16, 1993, my youngest son, Richard [*the child's name has been changed to respect this family's privacy*], fell in a canal and nearly drowned. As a result, he has severe mental and physical handicaps. The early intervention center became involved about 2 weeks after the accident and just before Richard was released to go home. The center staff's sensitivity and quick response to our needs were tremendous. . . .

The therapy was so beneficial! [A staff member] could get him to relax and showed us how to hold him and position him to encourage this. After 6 to 8 weeks this child, who "should be" dead, could actually be held, could sleep for short periods on a more regular basis, and was beginning to attend to my voice. I was able to transport him and begin physical therapy and speech therapy at the center. Budget cuts precluded any more home visits.

Over the year, Richard has made so many improvements. He is able to swallow, activate a switch with his left hand, sit with some support, indicate yes and no, and is trying — unsuccessfully, but is trying — to crawl. He can also roll over.

All of the staff members at the early intervention center were so aware of Richard's needs and our family's needs. . . . They were full of encouragement, and helped me make informed decisions in areas where I had no experience. They taught me how to care for his needs, how to do therapy at home, and how to encourage his social development. They explained how to use the Medicaid system. Basically, they helped us as a whole family to have control over our lives and to have fun again. We will be forever grateful.

What Are the Future Challenges for the Part H Program?

Among the most important challenges and goals for states are developing services that are supportive of families, ensuring adequate numbers of qualified personnel, and improving fiscal management and accountability.

Family Support Needs to Be Further Strengthened.

States will continue to increase their capacity to identify all eligible children as early in their lives as possible and to provide quality services to those children and their families. States have identified the following activities among their current and future efforts to achieve their goals to support families:

- developing flexible service delivery options to meet the varied needs of children and families;
- strengthening the capacity of local programs to provide family-centered early intervention and support services, especially in rural and poorly accessible areas;
- implementing practices that meet the needs of all families, especially low income, isolated, and minority populations;
- intensifying and diversifying outreach and child find efforts;
- continuing to integrate Part H requirements into existing services and programs;
- expanding services to children at risk for developing delays;
- developing transition models that will create a seamless system in which families experience smooth transitions between service systems and programs;
- ensuring that infants and toddlers and their families have access to quality service coordination that meets their needs; and
- ensuring that parent/professional collaboration occurs at all levels of state and local service planning.

Without the concerted national efforts and incentives that accompanied the Program for Infants and Toddlers with Disabilities, one can clearly state that little, if any, of the extraordinary progress that has been made in Tennessee would have happened.

Director of Early Childhood Programs from Tennessee

Maintain the Quality of the Early Intervention System and Its Services.

Assuring a quality early intervention system and services is a priority for states. Efforts to assure quality include:

- definition and clarification of best practice guidelines and of the parameters and scope of early intervention services;
- development of ongoing quality assurance review and program evaluation processes that will effect change and measure results; and

- refinement of the early intervention service system based on evaluation results, current best practices, and compliance with Part H standards.

Assure that Personnel Are Fully Qualified

Ensuring adequate numbers of qualified and competent personnel is an ongoing challenge for state and jurisdictional early intervention systems. To achieve this, states are concentrating their efforts on the following activities:

We are a family deeply impacted by the values and vision of people who worked to make a certain part of a law really mean something for children and their families.

Parent and ICC Chair from Colorado

- developing professional, paraprofessional, and parent inservice education in collaboration with service providers, professionals, families, and credentialing organizations;
- developing a variety of pre-service training experiences and recruitment incentives in collaboration with institutions of higher education to address personnel shortages;
- establishing a competency-based system for certification of all early intervention personnel to insure that they meet the highest state standards;
- emphasizing a role for parents as professional or paraprofessional service providers;
- using mentors from all levels of involved disciplines;
- clarifying the role of the service coordinator in a growing system; and
- attracting a more diverse group of trained professionals to increase the capacity of the system's cultural competence.

Assure Adequate Funding for the Early Intervention System and Its Services.

States must continue to creatively use existing resources and seek additional resources to support the early intervention system. At the same time states are evaluating their systems and programs in order to refine practices and procedures and provide the highest quality of services to families. In order to achieve these goals, states identified the following areas on which to focus efforts:

- coordination and realignment of existing resources, including formal and informal community resources;
- inclusion of early intervention services in managed care programs;
- development of quality fiscal management and monitoring practices at the state and local levels; and
- maintenance of interagency coordination to reduce fragmentation and duplication of services and the enhancement of interagency agreements to support this effort.

Moving Part H Into the 21st Century

Services early in life of a child with special needs gives them an extra boost that, in many cases, will allow them to lead a more normal life as they grow older. It is very likely that a little effort up front with young children will result in a much lower need for services as the child progresses through the education system to adult life.

Parent from Utah

Through the passage of P.L. 99-457 and the current amendments to IDEA, Congress has established a national agenda to expand the opportunities and prevention benefits of early intervention services to many more young children with special needs and their families in all of our nation's communities in urban, suburban, rural, and remote areas. In particular, Congress has encouraged states to enhance child development, maximize inclusive practices, and support families in a partnership role throughout the planning and provision of services. This Federal-state-local partnership has created a framework for local comprehensive service systems. Structures have been planned and put in place, and now are being widely implemented.

This legislative agenda marks another important step in Congress' willingness to address the needs of people with disabilities and their families. The promises and expectations of Part H of IDEA, although not fully realized, have become a reality, through the development of partnerships among families, governmental agencies, and public and private providers. Through continued needed resources, the intent of the law — a contract with American citizens to meet the needs of their infants and children with disabilities and families — will be fully realized in the next century.

With the passage of the ADA [Americans with Disabilities Act], we as a society make a pledge that every child with a disability will have the opportunity to maximize his or her potential to live proud, productive, and prosperous lives in the mainstream of our society.

But without appropriate early intervention, preschool, and special education services provided under IDEA this promise will not be realized for many newborn infants and older children with disabilities. Part H, which we are reauthorizing today, and which has been called "the most important children's disability legislation of the decade," provides these services while maintaining a focus on the family.

Senator Tom Harkin (D., IA)
Congressional Record, September 16, 1991, p. S13072.

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Appendix 3, Part H Coordinators and ICC Chairs, *continued*

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APPENDIX 4

Status of States and Jurisdictions for Eighth Year Funding (FY1994) of Part H of IDEA

(Awarded by OSEP as of March 31, 1995)

States/Jurisdictions Approved for Full Implementation (*n=26*)

Alaska (1993-95)
Arizona (1993-95)
Colorado (1992-1994)
Florida (1994)
Hawaii (1992-1994)
Idaho (1992-1994)
Illinois (1993-1995)
Louisiana (1993-95)
Maryland (1992-1994)
Massachusetts (1992-1994)
Missouri (1994)
Montana (1993-95)
Nevada (1993-1995)
New Hampshire (1993-95)
New Jersey (1994)
North Carolina (1993-95)
Ohio (1992-94)
Oklahoma (1992-1994)
Rhode Island (1993-95)
South Dakota (1993-95)
Tennessee (1992-94)
Texas (1993-95)
Utah (1992-94)
West Virginia (1993-95)
Wisconsin (1993-95)
Wyoming (1992-94)

Status of States and Jurisdictions for Seventh Year Funding (FY1993) of Part H of the IDEA

(Awarded by OSEP as of September 30, 1994)

States/Jurisdictions Approved for Full Implementation *(n=54)*

Alabama (1993)
Alaska (1993-1995)
American Samoa (1992-1994)
Arizona (1993-1995)
Arkansas (1992-1994)
California (1993)
Colorado (1992-1994)
Connecticut (1993-1995)
Delaware (1993)
District of Columbia (1993)
Florida (1993)
Georgia (1993)
Guam (1992-1994)
Hawaii (1992-1994)
Idaho (1992-1994)
Illinois (1993-1995)
Indiana (1993)
Iowa (1993-1995)
Kansas (1992-1994)
Kentucky (1993)
Louisiana (1993-1995)
Maine (1993)
Maryland (1992-1994)
Massachusetts (1992-1994)
Michigan (1993-1995)
Minnesota (1993)
Mississippi (1993)
Missouri (1993)
Montana (1993-1995)
Nebraska (1993)
Nevada (1993-1995)
New Hampshire (1993-1995)
New Jersey (1993)
New Mexico (1993-1995)
New York (1993-1995)
North Carolina (1993-1995)
North Dakota (1993)
Ohio (1992-1994)
Oklahoma (1992-1994)
Oregon (1993-1995)
Pennsylvania (1992-1994)
Puerto Rico (1993)
Rhode Island (1993-1995)
South Carolina (1993)
South Dakota (1993-1995)
Tennessee (1992-1994)
Texas (1993-1995)
Utah (1992-1994)
Vermont (1993)
Virginia (1993-1995)
Washington (1993)
West Virginia (1993-1995)
Wisconsin (1993-1995)
Wyoming (1992-1994)

Notes:

- The year(s) reflect the different submission options for the Federal fiscal year (i.e., annual or 3-year).
- Part H grant award is made through a consolidated grant under Chapter 2 of the Ed. Consolidation and Improvement Act of 1981 to Northern Marianas, Palau, and Virgin Islands.
- The Department of Interior (DOI) receives Part H allocation which then is distributed by DOI to tribes.
- Federated States of Micronesia and Republic of Marshall Islands are not currently eligible for this federal program.

APPENDIX 5

NEC*TAS List of Part H Lead Agencies

State/Jurisdiction[1,2]	Lead Agency
Alabama	Rehabilitation Services
Alaska	Health & Social Services
American Samoa	Health
Arizona	Economic Security
Arkansas	Human Services/Developmental Disabilities (DD)
California	Developmental Services
Colorado	Education
Commonwealth of No. Mariana Islands[3]	Education
Connecticut	Education
Delaware	Health and Social Services
District of Columbia	Human Services
Florida	Health & Rehabilitative Services
Georgia	Human Resources/Division of Health
Guam	Education
Hawaii	Health
Idaho	Health & Welfare/DD
Illinois	Education
Indiana	Family and Social Services
Iowa	Education
Kansas	Health and Environment
Kentucky	Human Resources/Mental Health-Mental Retardation (MH-MR)
Louisiana	Education
Maine	Education
Maryland	Governor's Office of Children, Youth and Families
Massachusetts	Public Health
Michigan	Education
Minnesota	Education
Mississippi	Health
Missouri	Education
Montana	Social and Rehabilitation Services/DD
Nebraska	Education and Social Services (Co-Lead)
Nevada	Human Resources
New Hampshire	Health and Human Services
New Jersey	Health
New Mexico	Health/DD
New York	Health
North Carolina	Human Resources/MH-DD-Substance Abuse Services (SAS)
North Dakota	Human Services
Ohio	Health
Oklahoma	Education
Oregon	Education
Palau[3]	Education
Pennsylvania	Public Welfare
Puerto Rico	Health
Rhode Island	Health
South Carolina	Health & Environmental Control
South Dakota	Education
Tennessee	Education
Texas	Interagency Council on Early Childhood Intervention
Utah	Health
Vermont	Education and Human Services (Co-Lead)
Virgin Islands[3]	Education with Memo of Understanding (MOU) to Health
Virginia	MH/MR/SAS
Washington	Social & Health Services
West Virginia	Health & Human Services
Wisconsin	Health & Social Services
Wyoming	Health

[1] Federated States of Micronesia and Republic of Marshall Islands are not currently eligible for this federal program.

[2] The Department of the Interior (DOI) receives Part H allocation which then is distributed by DOI to tribes.

[3] Part H grant award is made through a consolidated grant under Chapter 2 of the Education Consolidation & Improvement Act of 1981.